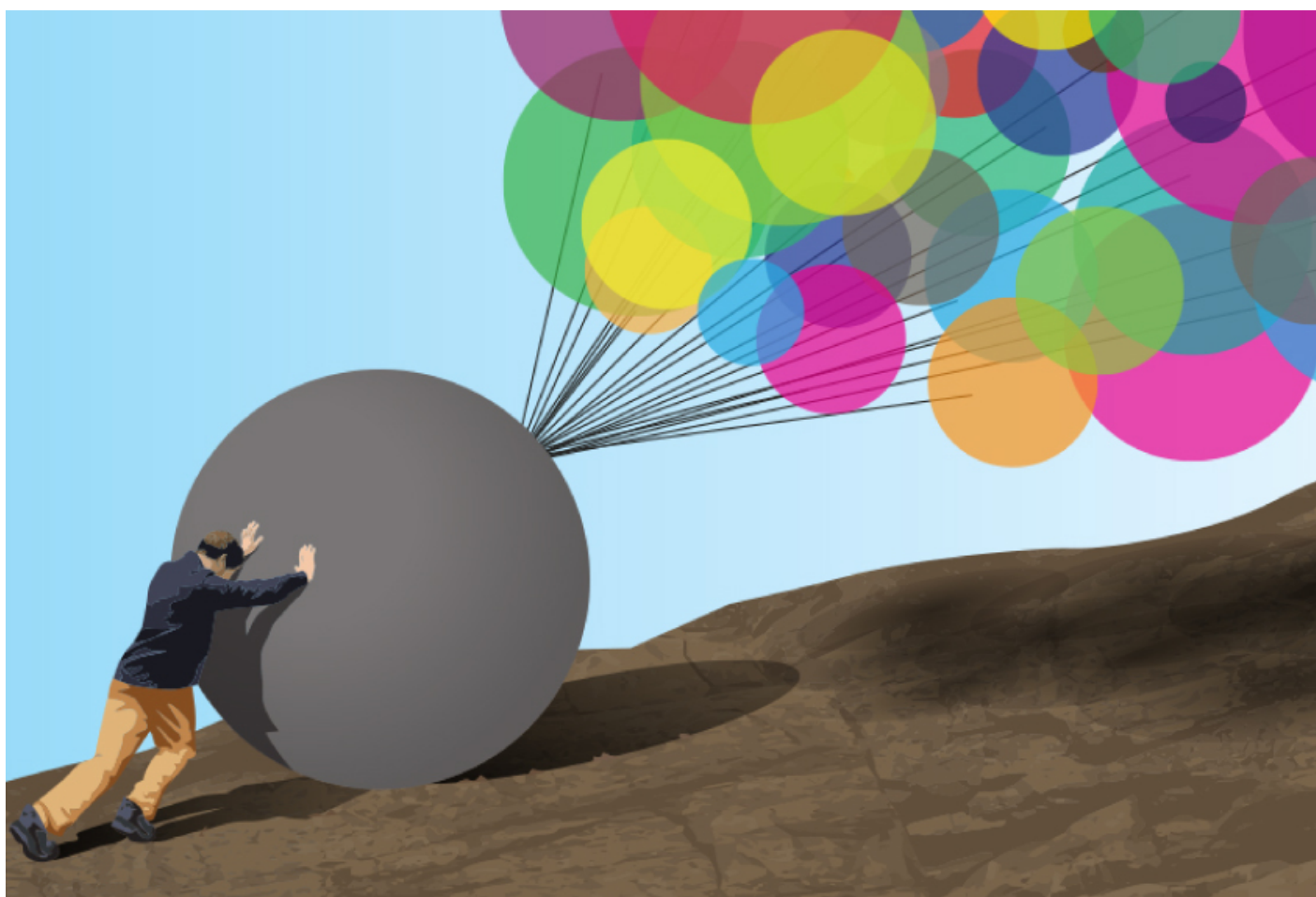


VIEWPOINT

How to help young adults with autism transition to adulthood

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For the past 20 years, my colleagues and I have run a social-skills group for children with autism, ages 5 to 18 years. Our program teaches the children how to recognize their own emotions, have conversations, solve problems and build genuine friendships.

About five years ago, some of those who had finished the program reached out to us for help navigating the adult world. They were concerned about the challenges involved in attending college, picking a career path, succeeding in the workplace, living independently and forming social and romantic relationships. There were few resources available to them.

Adults with autism report poorer social and vocational outcomes than any other disability group^{1,2}. They often don't earn a living wage, have a partner or family, or participate in the community. They also frequently contend with physical and mental **health problems**.

My colleagues and I wanted to help these young people. We created a curriculum for young adults with autism that helps them to better manage the stress and challenges associated with the transition to adulthood. It also teaches their parents and other helpers how to assist them in learning and implementing skills.

We first analyzed the literature on interventions used in adults with **schizophrenia**, who have similar problems adapting to the demands of adult life. Based on those, we developed a 20-week program for young adults with autism. The program combines an age-appropriate version of our social-skills curriculum with a unit called Functional Adaptive Skills Training, developed at the University of California, Los Angeles, that teaches social, organizational and other daily-living skills in a group format³.

Our pilot trial included 13 participants with autism aged 18 to 24, with no control group. Parents of the participants also met weekly to discuss their adult child's difficulties and attended lectures about adult services. Our unpublished results suggest that the young adults and their parents had high levels of satisfaction with the training. The participants also reported an improvement in their planning and organizing skills, and some relief from depression.

Version 2.0:

My team and our collaborators have also developed a second-generation program that includes modules on handling stress and developing coping skills. The goal is to prevent young adults from avoiding situations — a behavior we believe accounts for the discouraging statistics on social and vocational outcomes.

Our 20-week program, ACCESS, includes groups for both young autistic adults and their 'social coaches,' such as parents and partners. The curricula and assignments are designed to give these dyads opportunities to interact in a mature, egalitarian and collaborative way.

Four introductory lessons teach foundational concepts, such as understanding different social circles, the idea that social behavior differs based on context and that adults relate to family members, friends and bosses in different ways. The lessons also include active listening and giving and receiving feedback.

The second module consists of six lessons that teach techniques based on principles of cognitive behavioral therapy (CBT) for dealing with negative feelings and engaging in uncomfortable situations instead of avoiding them. The third module includes five lessons designed to help participants better understand and build relationships with friends and to clarify that the rules for relating to friends are different than those used when relating to a boss or parent, again using CBT techniques to engage instead of avoid.

The last four lessons center on the workplace. They focus on adopting a 'can-do' attitude, being aware of social circles involving colleagues and bosses, and giving and receiving feedback on the job. Participants also are required to have some form of paid or volunteer job, and to complete weekly assignments with their social coaches.

We conducted a trial of the program using participants on the waiting list as a control group. Our analysis included 41 people, aged 18 to 38 years, who have a verified autism diagnosis and an intelligence quotient greater than 70⁴. Participants were randomized to our intervention or to a treatment-as-usual control group. People in the latter group received the intervention six months after the trial. We assessed participants and social coaches, using questionnaires to measure social and adaptive functioning, self-determination, self-efficacy and anxiety.

Lessons learned:

The results of the trial were modest but encouraging. Although participants did not report a decline in anxiety, their global adaptive functioning improved, according to their social coaches. The improvements were driven by gains in home living skills, such as taking responsibility for cleaning, property maintenance, food preparation and other household chores. The social coaches also reported improved communication and self-direction, as well as self-determination skills such as goal-setting, planning and self-advocacy.

The participants reported greater confidence in their ability to ask for social support from family, and even friends, in times of stress. As before, their satisfaction with the intervention was extremely high.

The trial taught us important lessons. First, although it is never too early to help people with autism develop the adaptive, social, vocational and self-determination skills they will need in adult life, some of these skills may need to be relearned at key transition periods. Many of our participants had been members of our child and adolescent social-skills groups, but they needed to learn to adapt the skills for adult contexts. Similarly, many of the parent social coaches remarked that as their children became young adults, they needed to retool their skills as advocates, given the dramatic changes to the service network.

Second, we found that 20 weeks is not enough to teach about adult life. We frequently joked that any group of lessons could be expanded into its own curriculum. Third, the participants reported

that the most valuable components of the program are learning about the work environment, learning organizational skills and coming to appreciate how they engaged in distorted, and typically negative, thinking about their own strengths and challenges.

We also marveled at how the parents in our study navigated the balance between enabling independence and ensuring the safety of their adult children. For example, one of the parents in our group allowed her son to travel alone to New York City to visit a friend. This experience made him feel strong and independent and eased his depression. Helping parents safely allow their children to be more independent has the potential to be an important new area for research.

This year, we are continuing to offer the program on a fee-for-service basis. We hope to eventually write and publish a manual for an intervention that could be used more widely for young autistic adults anywhere.

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